The Patient's Perspective in Cirrhosis: Unmet Supportive Care Needs Differ by Disease Severity, Etiology, and Age

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Patients with cirrhosis have significant physical, psychological, and practical needs. We documented patients' perceived need for support with these issues and the differences with increasing liver disease severity, etiology, and age. Using the supportive needs assessment tool for cirrhosis (SNAC), we examined the rate of moderate-to-high unmet needs (Poisson regression; incidence rate ratio [IRR]) and the correlation between needs and sociodemographic/clinical characteristics (multivariable linear regression) in 458 Australians adults with cirrhosis. Primary liver disease etiology was alcohol in 37.6% of patients, chronic viral hepatitis C in 25.5%, and nonalcoholic fatty liver disease (NAFLD)/ nonalcoholic steatohepatitis (NASH) in 23.8%. A total of 64.6% of patients had Child-Pugh class A cirrhosis. Most patients (81.2%) had at least one moderate-to-high unmet need item; more than 25% reported a moderate-to-high need for help with "lack of energy," "sleep poorly," "feel unwell," "worry about … illness getting worse (liver cancer)," "have anxiety/stress," and "difficulty with daily tasks." Adjusting for key sociodemographic/clinical factors, patients with Child-Pugh C had a greater rate of "practical and physical needs" (vs. Child-Pugh A; IRR = 2.94, 95% confidence interval [CI] 2.57-3.37), patients with NAFLD/NASH had a greater rate of needs with "lifestyle changes" (vs. alcohol; IRR = 1.81, 95% CI 1.18-2.77) and "practical and physical needs" (IRR = 1.43, 95% CI 1.23-1.65), and patients aged ≥65 years had fewer needs overall (vs. 18-64 years; IRR = 0.70, 95% CI 0.64-0.76). Higher overall SNAC scores were associated with Child-Pugh B and C (both $P < 0.001$), NAFLD/NASH ($P = 0.028$), patients with "no partner, do not live alone" ($P = 0.004$), unemployment ($P = 0.039$), ascites ($P = 0.022$), and dyslipidemia ($P = 0.024$) compared with their counterparts. *Conclusion:* Very high levels of needs were reported by patients with cirrhosis. This information is important to tailor patient-centered care and facilitate timely interventions or referral to support services. (*Hepatology Communications* 2021;5:891-905).

Cirrhosis is the advanced stage of chronic liver disease, with the progression from "compensated" to "decompensated" cirrhosis characterized by the onset of complications,[1-3] which are associated with a substantial decrease in life expectancy.[4] Major complications associated with decompensated cirrhosis (ascites, hepatic encephalopathy, variceal bleeding) have a substantial impact on patients' activities of daily living and health-related quality of life (HRQOL).[5,6] Many patients

with decompensated cirrhosis experience symptoms ordinarily associated with end-stage cancer, such as anorexia and fatigue, and have HRQOL scores comparable to the "worst imaginable health state."[6,7] In addition, patients with cirrhosis may experience many other debilitating symptoms, including difficulty concentrating, pruritus, muscle cramps and insomnia, which may also lead to lower HRQOL when compared to patients without liver disease.

Cirrhosis and its complications have a substantial economic, social, and personal impact on the affected patient.[8] Receiving a diagnosis of cirrhosis and its subsequent treatment may present many psychological, physical, and practical challenges for the patient and their family. Patients with cirrhosis, particularly decompensated cirrhosis, often follow complex medication regimens and dietary restrictions,[9] and experience undesirable life impacts such as a reduction in their capacity to undertake activities of daily living, and high levels of anxiety and stress.[10-12] In particular, patients with cirrhosis worry about development of liver cancer, disease symptoms and treatment, as well as the impact of the disease on social interactions and their ability to function effectively at home and/or work.[13,14]

A key aspect of management for all patients with cirrhosis is supportive care and alleviation of symptoms. However, among patients with cirrhosis, there is little information on the extent of supportive care needs.[15] These data are important to tailor patient-centered care and facilitate timely interventions or referral to appropriate support services. 'Supportive care needs" is a broad term used to refer to patients' perceived needs for management of general physical and psychological health, spiritual, practical, social, information, and cultural needs.[15,16] Supportive care is increasingly seen as a core component of patient-centered care, and addresses a wide range of patient needs. These issues are best described by the people who experience them, as patients' perceptions of their disease and treatment response may differ markedly from clinicians' assessments.

To address the paucity of data on patient-reported outcomes during the management of cirrhosis, we documented patients' perspectives of their unmet supportive care needs and the differences with increasing disease severity, patient age group, and disease etiology. Using a validated supportive needs assessment tool for cirrhosis (SNAC),[17] the aim of the study was to measure, explore, and assess the type and level of perceived supportive needs of people living with cirrhosis, and examine the correlation between these needs and a range of sociodemographic and clinical characteristics.

Patients and Methods

SETTING AND PARTICIPANTS

Details of the CirCare study, a multicenter study of patients with cirrhosis, have been described previously.[17] Briefly, consecutive adult patients attending hepatology/gastroenterology clinics or admitted to one of five hospitals in Brisbane, Queensland, between June 2017 and December 2018, with a diagnosis of cirrhosis were eligible to participate. A study nurse and the treating clinicians assessed patients' eligibility. Patients with cognitive or physical impairment that could interfere with participation, or an inability to communicate in English (if an interpreter was not available to assist with the interview) were excluded.

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DATA COLLECTION AND MEASURES

Patient interviews were conducted face to face at recruitment, or by self-administered questionnaire when practical time constraints prevented face-to-face completion. For the latter, the SNAC instructions guided patients to fill in data specific to them (e.g., whether they had this issue or concern, how much additional help they needed). The SNAC and its instructions are provided as Supporting Information. Clinical data were obtained from the patients' medical records by clinicians (S.A., B.M., E.E.P., A.L., and L.P.) using a structured data collection form.

Sociodemographic data (e.g., marital status, education level, country of birth, place of residence) were self-reported at recruitment. Place of residence was categorized according to rurality of residence[18] and the Index of Relative Socioeconomic Advantage and Disadvantage.[19]

SNAC[17] was used to assess needs across four subscales: "psychosocial issues" (14 items), "practical and physical needs" (16 items), "information needs" (7 items), and "lifestyle changes" (2 items). This tool asks participants to rate their need for help with each item over the past month. Responses to each item are broken down to a "yes" or "no" initial response to the opening question ("In the past month, did you …"), followed by a Likert scale with four possible answers ("None," "A little," "Some," and "A lot") to the subsequent question ("How much additional help did/do you need?"). The SNAC response categories to the initial "yes" or "no" response to the opening question and the subsequent question with four possible answers were re-scored using a five-point response scale ("0" indicates no issue with that item, no need for help; "1" indicates an issue with that item and no help required; "2" indicates an issue with that item and "a little" help required; "3" indicates an issue with that item and "some" help required; and "4" indicates an issue with that item and "a lot" of help required). Missing values for individual items were imputed using the participant's mean value for the relevant section of the questionnaire, provided that data were available for more than one half of the items in that section. The mean score for each subscale and the overall SNAC mean score (average of the four subscales) can range from 0 (indicating no issue with all items in the SNAC tool) to a possible maximum value of 4.

Severity of disease was classified using the Child-Pugh class (calculated on the day of recruitment) and by absence (compensated cirrhosis) versus presence (decompensated) of cirrhosis complications (e.g., ascites, hepatic encephalopathy, variceal bleeding, jaundice).

STATISTICAL ANALYSIS

Analyses were conducted using Stata/SE (version 15; Stata Corporation, College Station, TX). Descriptive analyses are presented as frequency (percentages), mean (SD), or median (interquartile range [IQR]) value, depending on data distribution. Linear regression analyses (bivariable) were performed to study the independent influence of each variable on the level of needs (summary scales of the overall SNAC score and the scores for each subscale). As variables *marital status* and *live alone* were confounded (all patients who were "married/*de facto*" did not live alone), these variables were combined and categorized as "have a partner, do not live alone," "no partner, do not live alone," or "no partner, live alone."

In multiple regression analysis, the need scores (overall and for each subscale) were used as dependent variables, and demographic and clinical variables were used as independent variables. The final multivariable model was determined based on the results of the bivariable analysis, but also taking into account our understanding of the relationships and dependencies among variables as well as their clinical relevance. For example, at bivariable analysis, there was a strong correlation between age and SNAC scores. Moreover, patients' needs varied depending on whether they were of working age (18-64 years) or retirement age (≥65 years), and patient profile varied depending on primary liver disease etiology and severity of disease (assessed using Child-Pugh class). These variables were adjusted for by inclusion in the model. Recruitment hospital, place of residence, and combined marital/live alone status were also adjusted for by inclusion in the model, because they may be important factors with regard to support or access to community services. Finally, diabetes was included as an indicator of comorbidity risk, as it is a common comorbid condition in patients with cirrhosis and is associated with adverse patient outcomes including morbidity and mortality.[20] The final model included Child-Pugh class, age group, recruitment hospital, marital/live alone status, place of residence, diabetes,

and primary liver disease etiology. Multivariable linear regression analyses reported in terms of adjusted β coefficients with associated 95% confidence intervals (CIs) were used to assess the independent effect of demographic (e.g., age) and clinical variables (e.g., disease severity) on the SNAC. Positive β values for variables denote an increase in SNAC score compared with the reference group, whereas negative β values denote a decrease in SNAC score.

The level of perceived supportive needs for each item was grouped as "moderate to high" if patients reported that they needed "some" or "a lot" of additional help with that item. The *rate* of moderate-to-high unmet needs was defined as the number of moderate-to-high items in a subscale or overall divided by the total number of items in that subscale or overall. To compare the rate of moderate-to-high unmet needs according to Child-Pugh class, age group, or primary liver disease etiology group, Poisson regression was undertaken to calculate the ratio of rates; incidence rate ratio (IRR) and 95% CIs are reported. The significance of variables in the Poisson regression modeling was assessed using Wald tests. The multivariable models included Child-Pugh class, age group, recruitment hospital, marital/live alone status, place of residence, diabetes, and primary liver disease etiology.

To assess statistical differences between the categorical variable "reporting of at least one moderate-to-high unmet need" versus "not" by age group and primary liver disease etiology groups, multivariable logistic regression analysis was used to adjust for Child-Pugh class; adjusted *P* values are reported. Statistical significance was set at alpha = 0.05, and all *P* values were two-sided.

ETHICAL APPROVAL

Approval was obtained from the Human Research Ethics Committees of the Metro South Health (HREC/16/QPAH/628) and QIMR Berghofer Medical Research Institute (P2207).

Results

PARTICIPANT CHARACTERISTICS

Details of the CirCare study have been previously described.[17] Briefly, 746 patients were invited to participate in the study (581 interviewed, 78% response). After missing values for individual items were imputed, 465 patients had complete SNAC data; however, 7 patients with assumed chronic liver disease were excluded because they did not have cirrhosis. A total of 458 patients were included in the analysis. The characteristics of the study sample are given in Table 1.

Most patients (84.3%) were recruited from outpatient clinics at the selected hospitals; 15.7% were recruited following a hospital admission to treat complications of cirrhosis, and 17.7% had a career or support person present during the interview. Most patients (94.1%) completed the whole interview face to face; due to practical issues in the clinical setting (e.g., patient scheduled for imaging or a procedure), 5.9% had part of the interview conducted over the telephone or self-completed and posted back to the researchers. About half of the patients (53.9%) were recruited from Princess Alexandra Hospital (the major tertiary liver center in Queensland), 18.1% from Royal Brisbane and Women's Hospital, 10.7% from Prince Charles Hospital, 9.2% from Logan Hospital, and 8.1% from Mater Hospital. Most patients (71.0%) were male with a mean age of 59.3 (SD = 11.0) years.

Alcohol-related cirrhosis was the primary liver disease etiology for 37.6% of patients, followed by hepatitis C virus (HCV) in 25.5% and nonalcoholic fatty liver disease (NAFLD)/nonalcoholic steatohepatitis (NASH) in 23.8%. About two-thirds of the patients had Child-Pugh class A at recruitment (64.6%); 22.7% had class B; and 12.7% had class C. One-third of the patients (33.2%) had at least one cirrhosis complication documented in their medical notes at recruitment (decompensated disease). Ascites (26.0%) and jaundice (18.3%) were the most common complications. Diabetes was present in 42.1%, and 70.3% of patients were overweight or obese.

PREVALENCE OF SUPPORTIVE NEEDS OVERALL

The overall SNAC score (calculated by the average score of the four subscales) was not normally distributed and ranged from 0 (indicating no issue with all items in the SNAC tool) to 3.11 (indicating higher supportive care needs) with a possible maximum value of 4. The median SNAC score for the study cohort was 0.8 (IQR 0.4-1.4), with the highest score for "practical and physical" needs (median = 0.8, IQR 0.3-1.6),

TABLE 1. PATIENT DEMOGRAPHIC AND CLINICAL CHARACTERISTICS AT RECRUITMENT

		N = 458
Age group	18-64 years	305 (66.6%)
	≥65 years	153 (33.4%)
Gender	Female	133 (29.0%)
	Male	325 (71.0%)
Marital status	Married/*de facto*	219 (47.8%)
	No partner	239 (52.2%)
Live alone	No	332 (72.5%)
	Yes	126 (27.5%)
First language	English	392 (85.6%)
	Not English	66 (14.4%)
Education*	Junior high school or less	195 (42.9%)
	Senior high school	93 (20.4%)
	Trade/diploma or higher	167 (36.7%)
Current employment	Employed	101 (22.1%)
	Unemployed	357 (77.9%)
Country of birth	Australia	325 (71.0%)
	Overseas	133 (29.0%)
Socioeconomic status†	Q1 most affluent	95 (20.8%)
	Q2	140 (30.6%)
	Q3	68 (14.9%)
	Q4	79 (17.3%)
	Q5 Most disadvantaged	75 (16.4%)
Rurality of residence	Major city	395 (86.8%)
	Outside major city area	60 (13.2%)
Primary liver disease etiology	Alcohol	172 (37.6%)
	Hepatitis C virus	117 (25.5%)
	NAFLD/NASH	109 (23.8%)
	Hepatitis B virus	26 (5.7%)
	Other	34 (7.4%)
Child-Pugh class‡	A	285 (64.6%)
	B	100 (22.7%)
	C	56 (12.7%)
Presence of complications of cirrhosis	Compensated	306 (66.8%)
	Decompensated	152 (33.2%)
Portal hypertension		307 (67.0%)
Varices		215 (46.9%)
Ascites		119 (26.0%)
Jaundice		84 (18.3%)
Liver cancer§		59 (12.9%)
Encephalopathy		41 (9.0%)
Comorbidities		
Diabetes‖		193 (42.1%)
Hypertension		163 (35.6%)
Dyslipidemia		106 (23.1%)
Anxiety and/or depression		110 (24.0%)

TABLE 1. *Continued*

		N = 458
Body mass index	Normal/underweight	136 (29.7%)
	Overweight	116 (25.3%)
	Obese/morbidly obese	206 (45.0%)

*Information was missing for 3 patients.
†Information was missing for 1 patient.
‡Unable to calculate Child-Pugh score for 17 patients.
§Fifty-seven (96.6%) were hepatocellular carcinoma, 2 (3.4%) were cholangiocarcinoma, and information was missing for 3 patients.
‖A total of 192 patients had type 2 diabetes, and 1 had type 1 diabetes.

followed by "information needs" (median = 0.7, IQR 0.1-1.3), "psychosocial issues" (median = 0.6, IQR 0.2-1.5), and "lifestyle changes" (median = 0.5, IQR 0.0-1.5).

Overall, 100% of patients reported having an issue with at least one item in the SNAC tool; these needs were both "met" (had an issue with that item, but did not need additional help) and "unmet" (had an issue with that item and additional help was required). Items for which at least 1 in 5 patients had an issue but the need was met included "access professional help/counseling" (40.0%), "… informed about support groups in your area" (39.3%), "obtain information to use at home about how to manage your illness and complications" (38.2%), "have easy bruising, bleeding, thinning of the skin: (27.7%), "have lack of energy, tiredness" (25.1%), "make diet changes" (22.3%), and "worry about the worries of those close to you" (21.2%). The SNAC items stratified by the number and proportion of patients with met and unmet need is provided in Supporting Table S1.

Most patients (n = 402, 87.8%) reported needing additional help ("a little," "some," or "a lot") with at least one item, and 81.2% had at least one moderate-to-high unmet need item. The 20 most prevalent moderate-to-high unmet needs are given in Table 2 and include items across all subscales. Sixteen moderate-to-high unmet need items were reported by more than 20% of patients. More than 1 in 4 patients reported a moderate-to-high need for help with the following items: "lack of energy," "sleep poorly," "feel unwell," "worry about … illness getting worse (liver cancer)," "have anxiety/stress," and "difficulty with daily tasks."

TABLE 2. THE 20 MOST PREVALENT MODERATE-TO-HIGH UNMET SUPPORTIVE NEED ITEMS OVERALL AND ACCORDING TO CHILD-PUGH CLASS

| | | Child-Pugh Class* | | | | | |
| | | A | B | C | Total | | |
Rank[†]	Items[‡]	n = 285	n = 100	n = 56	n = 458	P Value**	Subscale
1	Lack of energy, tiredness	80 (28.1%)	50 (50.0%)	38 (67.9%)	171 (37.3%)	<0.001	Practical and physical needs
2	Sleep poorly	86 (30.2%)	50 (50.0%)	30 (53.6%)	168 (36.7%)	<0.001	Practical and physical needs
3	Feel unwell	62 (21.8%)	45 (45.0%)	32 (57.1%)	141 (30.8%)	<0.001	Practical and physical needs
4	Worry about your illness getting worse (liver cancer)	65 (22.8%)	33 (33.0%)	23 (41.1%)	123 (26.9%)	0.008	Psychosocial issues
5	Have anxiety and/or stress	64 (22.5%)	35 (35.0%)	21 (37.5%)	123 (26.9%)	0.010	Psychosocial issues
6	Difficulty with daily tasks around the house	49 (17.2%)	39 (39.0%)	26 (46.4%)	115 (25.1%)	<0.001	Practical and physical needs
7	Feel down or depressed	59 (20.7%)	28 (28.0%)	21 (37.5%)	109 (23.8%)	0.020	Psychosocial issues
8	Have lack of interest	49 (17.2%)	32 (32.0%)	25 (44.6%)	107 (23.4%)	<0.001	Psychosocial issues
9	Worry about the worries of those close to you	51 (17.9%)	32 (32.0%)	23 (41.1%)	106 (23.1%)	<0.001	Psychosocial issues
10	Fear of the unknown or uncertainty about the future	49 (17.2%)	35 (35.0%)	21 (37.5%)	106 (23.1%)	<0.001	Psychosocial issues
11	Swelling of ankles and legs	41 (14.4%)	34 (34.0%)	24 (42.9%)	102 (22.3%)	<0.001	Practical and physical needs
12	Feel frustrated	44 (15.4%)	34 (34.0%)	21 (37.5%)	102 (22.3%)	<0.001	Psychosocial issues
13	Have ascites	30 (10.5%)	36 (36.0%)	33 (58.9%)	100 (21.8%)	<0.001	Practical and physical needs
14	Have itchy skin	42 (14.7%)	34 (34.0%)	20 (35.7%)	98 (21.4%)	<0.001	Practical and physical needs
15	Make diet changes	39 (13.7%)	37 (37.0%)	16 (28.6%)	95 (20.7%)	<0.001	Lifestyle changes
16	Had loss of appetite, nausea, or vomiting	39 (13.7%)	26 (26.0%)	26 (46.4%)	92 (20.1%)	<0.001	Practical and physical needs
17	Decreased ability to get around	36 (12.6%)	29 (29.0%)	25 (44.6%)	91 (19.9%)	<0.001	Practical and physical needs
18	Informed about things you can do to help yourself	59 (20.7%)	19 (19.0%)	9 (16.1%)	89 (19.4%)	0.714	Information needs
19	Job performance decrease due to health	36 (12.6%)	25 (25.0%)	22 (39.3%)	86 (18.8%)	<0.001	Practical and physical needs
20	Bruised, bleeding, or thinning of the skin	36 (12.6%)	24 (24.0%)	24 (42.9%)	84 (18.3%)	<0.001	Practical and physical needs

*Unable to calculate Child-Pugh score for 17 patients.
**Bivariable logistic regression.
[†]Ranking based on overall proportion.
[‡]Simplified wording of items (refer to Supporting Table S1 for full wording).

These analyses were performed, when possible, to compare and contrast prevalence of unmet needs when stratified by liver disease severity, patient age group, and according to the three most common liver disease etiology groups: alcohol, HCV, and NAFLD/NASH.

HIGHER SUPPORTIVE NEEDS WITH INCREASING LIVER DISEASE SEVERITY

The median SNAC scores varied significantly by Child-Pugh class, with patients with Child-Pugh B and C having higher median scores than patients with Child-Pugh A (overall and for three subscales; Fig. 1). Almost all patients with Child-Pugh C (98.2%) had at least one moderate-to-high unmet need (Table 3). Patients with Child-Pugh A and B had higher information needs compared with Child-Pugh C, whereas patients with advanced cirrhosis had progressively higher "practical and physical needs" and "psychosocial issues."

In addition, the *rate* of moderate-to-high unmet needs overall, and for each of the four subscales, varied significantly by Child-Pugh class. Following adjustment for key sociodemographic factors (Table 3),
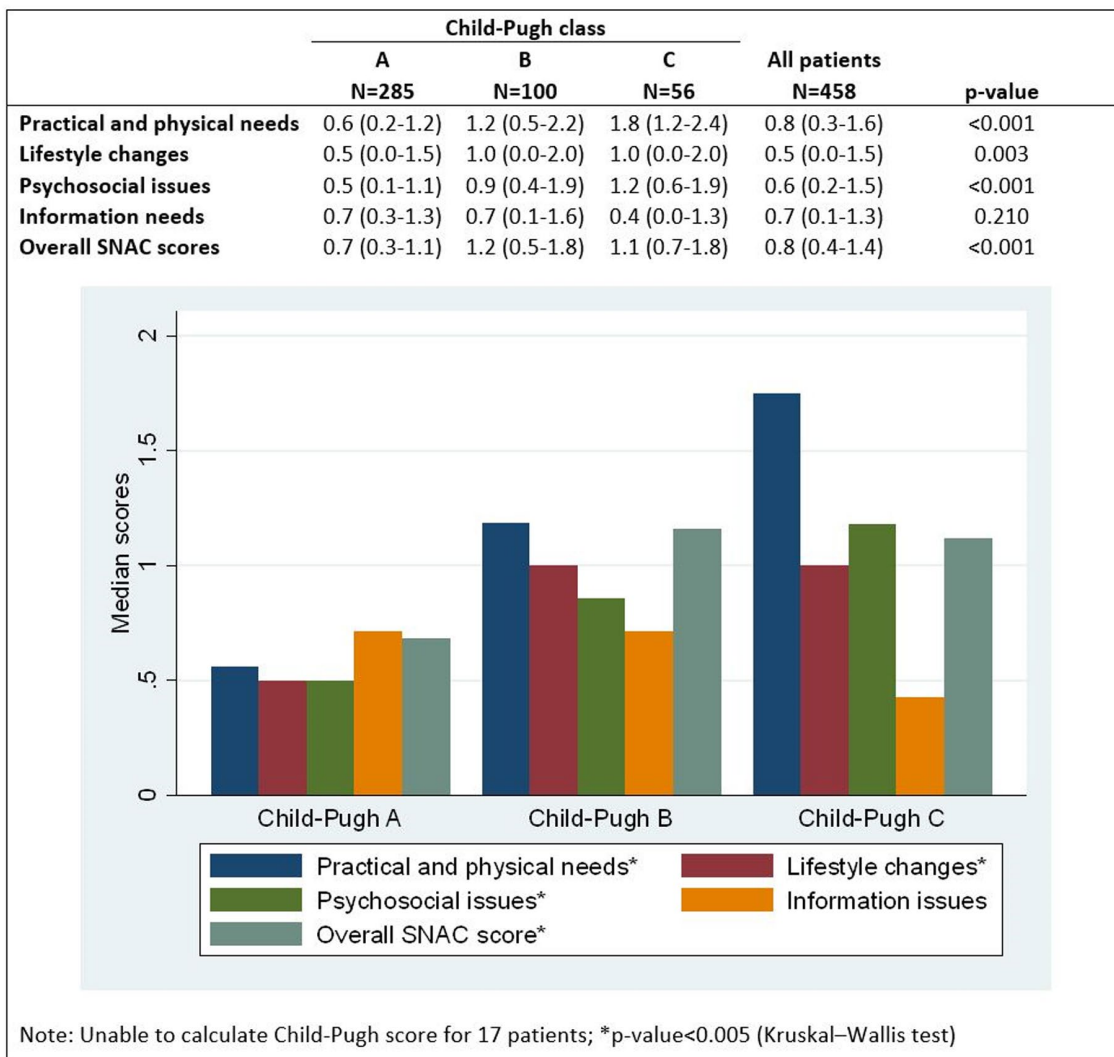
| | Child-Pugh class | | | | |
| | A | B | C | All patients | |
	N=285	N=100	N=56	N=458	p-value
Practical and physical needs	0.6 (0.2-1.2)	1.2 (0.5-2.2)	1.8 (1.2-2.4)	0.8 (0.3-1.6)	<0.001
Lifestyle changes	0.5 (0.0-1.5)	1.0 (0.0-2.0)	1.0 (0.0-2.0)	0.5 (0.0-1.5)	0.003
Psychosocial issues	0.5 (0.1-1.1)	0.9 (0.4-1.9)	1.2 (0.6-1.9)	0.6 (0.2-1.5)	<0.001
Information needs	0.7 (0.3-1.3)	0.7 (0.1-1.6)	0.4 (0.0-1.3)	0.7 (0.1-1.3)	0.210
Overall SNAC scores	0.7 (0.3-1.1)	1.2 (0.5-1.8)	1.1 (0.7-1.8)	0.8 (0.4-1.4)	<0.001

Note: Unable to calculate Child-Pugh score for 17 patients; *p-value<0.005 (Kruskal–Wallis test)

FIG. 1. Median SNAC scores according to Child-Pugh classification.

patients with Child-Pugh C and B cirrhosis had a higher *rate* of moderate-to-high unmet need items than Child-Pugh A, with greater differences for "practical and physical needs" (IRR = 2.94 [95% CI 2.57-3.37] for Child-Pugh C, and IRR = 1.97 [95% CI 1.76-2.21] for Child-Pugh B compared with Child-Pugh A). In contrast, patients with Child-Pugh A had a higher rate of unmet "information needs" than Child-Pugh C (IRR = 1.45, 95% CI 1.04-2.03, *P* = 0.029).

The prevalence of *all* moderate-to-high unmet supportive care needs reported by patients with cirrhosis according to Child-Pugh class is provided in Supporting Table S2).

INCREASED SUPPORTIVE NEEDS IN PATIENTS OF WORKING AGE

The median SNAC scores varied significantly by patient age group, with patients aged ≥65 years having lower median scores than patients of working age (18-64 years), except for "information needs." The median overall SNAC score was 0.6 (IQR 0.3-1.0) for ≥65 year-olds compared with 0.9 (IQR 0.5-1.6; *P* < 0.001 adjusted for Child-Pugh class) for patients of working age. The *rate* of moderate-to-high unmet need items also varied by patient age group (Table 3). Following adjustment for key sociodemographic factors, patients aged ≥65 years had 30%

TABLE 3. COMPARISON OF THE *RATE* OF MODERATE-TO-HIGH UNMET NEED ITEMS REPORTED BY PATIENTS ACCORDING TO CHILD-PUGH CLASS, AGE GROUP, AND PRIMARY LIVER DISEASE ETIOLOGY

	Child-Pugh Class				Age Group			Primary Liver Disease Etiology			
	A (n = 285)	B (n = 100)	C (n = 56)		18-64 Years (n = 305)	≥65 Years (n = 153)		Alcohol (n = 172)	HCV (n = 117)	NAFLD/NASH (n = 109)	
	n (%)	n (%)	n (%)	PValue*	n (%)	n (%)	PValue*	N (%)	N (%)	n (%)	PValue*
At least one moderate-to-high unmet need item (overall)	218 (76.5%)	87 (87.0%)	55 (98.2%)	0.003	261 (85.6%)	111 (72.5%)	0.014	140 (81.4%)	96 (82.1%)	92 (84.4%)	0.365
	Reference	IRR (95% CI)	IRR (95% CI)	PValue**	Reference	IRR (95% CI)	PValue**	Reference	IRR (95% CI)	IRR (95% CI)	PValue**
Practical and physical needs	1.00	1.97 (1.76-2.21)	2.94 (2.57-3.37)	<0.001	1.00	0.62 (0.56-0.70)	<0.001	1.00	1.09 (0.96-1.24)	1.43 (1.23-1.65)	<0.001
Lifestyle changes	1.00	2.00 (1.44-2.79)	1.90 (1.19-3.04)	0.001	1.00	0.48 (0.33-0.69)	<0.001	1.00	0.88 (0.58-1.33)	1.81 (1.18-2.77)	0.006
Psychosocial issues	1.00	1.66 (1.46-1.88)	1.95 (1.66-2.28)	<0.001	1.00	0.62 (0.54-0.71)	<0.001	1.00	1.08 (0.93-1.25)	1.14 (0.97-1.36)	0.244
Information needs	1.00	1.11 (0.89-1.37)	0.69 (0.49-0.96)	0.031	1.00	0.85 (0.69-1.05)	0.140	1.00	0.95 (0.74-1.21)	1.04 (0.79-1.35)	0.834
Overall SNAC	1.00	1.83 (1.68-1.98)	2.18 (1.97-2.40)	<0.001	1.00	0.70 (0.64-0.76)	<0.001	1.00	1.01 (0.94-1.13)	1.28 (1.14-1.42)	<0.001

Note: Unable to calculate Child-Pugh score for 17 patients.

*Bivariable logistic regression.

**Multivariable Poisson regression model included Child-Pugh class, age group, recruitment hospital, combined variable marital/live alone, place of residence, diabetes, and primary liver disease etiology.

fewer moderate-to-high unmet need items overall (IRR = 0.70, 95% CI 0.64-0.76, *P* < 0.001) than patients of working age. Regarding individual items, there were statistically significant differences for 11 of the 39 items between patients of working age compared with patients aged ≥65 years. "Lack of energy" (43.3%), "sleep poorly" (43.3%), and "feel unwell" (37.0%) were the most prevalent moderate-to-high unmet needs in patients aged 18-64 years. The 20 most prevalent moderate-to-high unmet needs according to age group are provided in Supporting Table S3).

HIGHER MODERATE-TO-HIGH UNMET NEEDS, PARTICULARLY "LIFESTYLE CHANGES" IN PATIENTS WITH NAFLD/NASH

Median SNAC scores did not vary significantly across the three most common liver disease etiology groups except for "lifestyle changes," for which the median scores were slightly different for NAFLD/NASH (median = 0.5, IQR 0.0-2.0) compared with alcohol (median = 0.5, IQR 0.0-1.5) and HCV (median = 0.5, IQR 0.0-1.5; *P* = 0.0271 adjusted for Child-Pugh class). However, the *rate* of moderate-to-high unmet need items varied significantly across the primary disease etiology groups overall, and for "lifestyle changes" and "practical and physical needs" (Table 3). Following adjustment for key sociodemographic and clinical factors (including diabetes), patients with NAFLD/NASH had 81% more moderate-to-high unmet need items (IRR = 1.81, 95% CI 1.18-2.77, *P* = 0.006) in the "lifestyle changes" subscale and 43% more moderate-to-high unmet need items in the "practical and physical needs" subscale (IRR = 1.43, 95% CI 1.23-1.65, *P* < 0.001) compared to patients with alcohol as the primary disease etiology.

As the needs of patients with NAFLD/NASH may be influenced by the presence of metabolic risk factors in addition to diabetes, we repeated the analysis also adjusting for body mass index, dyslipidemia, and hypertension. The *rate* of moderate-to-high unmet need items for patients with NAFLD/NASH were similar to the rates reported in Table 3. In particular, patients with NAFLD/NASH had 77% more moderate-to-high unmet need items (IRR = 1.77, 95% CI 1.13-2.75, *P* = 0.011) in the "lifestyle changes" subscale and 44% more moderate-to-high

unmet need items in the "practical and physical needs" subscale (IRR = 1.44, 95% CI 1.23-1.67, *P* < 0.001) compared to patients with alcohol as the primary disease etiology.

Regarding individual items, there were statistically significant differences according to primary etiology for 6 of the 39 items, with a higher proportion of patients with NAFLD/NASH reporting unmet needs for five of these items. "Lack of energy" (44.0%), "sleep poorly" (35.8%), and "difficulty with daily tasks" (30.3%) were the most prevalent moderate-to-high unmet needs in patients with NAFLD/NASH. The 20 most prevalent moderate-to-high unmet needs according to primary liver disease etiology are provided in Supporting Table S4).

CORRELATIONS AMONG UNMET NEEDS AND SOCIODEMOGRAPHIC AND CLINICAL FACTORS

In multivariate analysis with adjustment for age, recruitment hospital, marital/live alone status, place of residence, diabetes, and primary liver disease etiology, increased severity of cirrhosis was correlated with higher levels of unmet needs in all subscales, except for "information needs." Positive β values for Child-Pugh B and C denote an increase in SNAC score compared with Child-Pugh A. The overall SNAC score was increased by 0.48 in patients with Child-Pugh C (95% CI 0.28-0.69, *P* < 0.001) and by 0.38 in patients with Child-Pugh B (95% CI 0.22-0.54, *P* < 0.001) (Table 4), compared to patients with Child-Pugh A. Similar increased scores were seen for Child-Pugh B and C compared with Child-Pugh A for all subscales except "Information needs."

Positive β values denoting higher overall SNAC scores were seen for NAFLD/NASH as the primary liver disease etiology (vs. alcohol; *P* = 0.028), patients with "no partner, do not live alone" (vs. "have a partner/do not live alone"; *P* = 0.004), current unemployment (*P* = 0.039), ascites (*P* = 0.022), and dyslipidemia (*P* = 0.024), compared with their counterparts.

Positive β values denoting higher "practical and physical" scores were associated with Child-Pugh C (vs. Child-Pugh A; *P* < 0.001), "no partner, do not

TABLE 4. LINEAR REGRESSION COEFFICIENTS FOR OVERALL SNAC SCORES, AND FOR THE SUBSCALES "PRACTICAL AND PHYSICAL NEEDS," "LIFESTYLE CHANGES," "PSYCHOSOCIAL ISSUES," AND "INFORMATION NEEDS," SHOWING THE INFLUENCE OF DEMOGRAPHIC AND CLINICAL VARIABLES ON SCORES

Variables Included in the Model	Overall SNAC Score				Practical and Physical Needs				Lifestyle Changes				Psychosocial Issues				Information Needs			
	β	95%	CI	PValue	β	95%	CI	PValue	β	95%	CI	PValue	β	95%	CI	PValue	β	95%	CI	PValue
Recruitment hospital																				
PA Hospital	ref				ref				ref				ref				ref*			
A	0.09	-0.07	0.26	0.272	0.07	-0.12	0.26	0.483	0.13	-0.16	0.42	0.385	-0.02	-0.25	0.22	0.894	0.20	-0.03	0.43	0.086
B	0.14	-0.07	0.36	0.194	0.22	-0.03	0.46	0.082	0.03	-0.33	0.40	0.853	0.10	-0.20	0.40	0.500	0.22	-0.07	0.51	0.141
C	0.32	0.09	0.55	0.007	0.09	-0.17	0.36	0.483	0.36	-0.03	0.76	0.071	0.36	0.04	0.68	0.029	0.45	0.14	0.77	0.004
D	0.08	-0.14	0.31	0.467	0.15	-0.11	0.40	0.264	0.16	-0.23	0.55	0.421	-0.07	-0.39	0.24	0.653	0.10	-0.20	0.41	0.502
Age group																				
18-64 years	ref				ref				ref				ref				ref			
65+ years	-0.28	-0.43	-0.14	<0.001	-0.30	-0.47	-0.14	<0.001	-0.41	-0.66	-0.16	0.001	-0.32	-0.52	-0.12	0.002	-0.09	-0.29	0.10	0.356
Marital status/live alone																				
Have a partner/do not live alone	ref*				ref *				ref				ref*				ref			
No partner/do not live alone	0.23	0.07	0.38	0.004	0.24	0.06	0.42	0.007	0.22	-0.04	0.49	0.100	0.36	0.14	0.57	0.001	0.09	-0.12	0.30	0.420
No partner/live alone	-0.02	-0.17	0.14	0.816	-0.04	-0.22	0.13	0.630	0.05	-0.21	0.32	0.701	-0.05	-0.26	0.17	0.661	-0.03	-0.24	0.18	0.750
Child-Pugh class																				
A	ref*				ref*				ref*				ref*				ref			
B	0.38	0.22	0.54	<0.001	0.61	0.43	0.79	<0.001	0.46	0.19	0.73	0.001	0.40	0.18	0.62	<0.001	0.03	-0.18	0.25	0.749
C	0.48	0.28	0.69	<0.001	1.07	0.84	1.30	<0.001	0.39	0.04	0.74	0.028	0.55	0.26	0.83	<0.001	-0.08	-0.35	0.20	0.591
Place of residence																				
Major city	ref				ref				ref				ref				ref			
Outside major city area	-0.16	-0.35	0.03	0.096	-0.08	-0.30	0.13	0.445	-0.23	-0.56	0.10	0.167	0.03	-0.24	0.29	0.850	-0.36	-0.62	-0.10	0.006
Diabetes (no)	0.05	-0.09	0.20	0.458	0.09	-0.07	0.25	0.281	0.06	-0.18	0.30	0.619	0.10	-0.10	0.29	0.338	-0.03	-0.22	0.16	0.749
Primary liver disease etiology																				
Alcohol	ref				ref				ref				ref				ref			
HCV	0.02	-0.14	0.19	0.776	0.09	-0.10	0.29	0.331	-0.06	-0.35	0.23	0.694	0.02	-0.22	0.25	0.885	0.04	-0.18	0.27	0.707
NAFLD/NASH	0.21	0.02	0.40	0.028	0.28	0.07	0.49	0.010	0.42	0.10	0.74	0.009	-0.01	-0.27	0.25	0.961	0.14	-0.11	0.40	0.262
other	0.10	-0.15	0.36	0.430	0.36	0.07	0.65	0.014	-0.10	-0.54	0.33	0.639	0.18	-0.17	0.54	0.315	-0.03	-0.37	0.31	0.861
Hepatitis B virus	-0.12	-0.41	0.17	0.413	-0.06	-0.38	0.27	0.724	-0.03	-0.52	0.46	0.892	-0.02	-0.42	0.38	0.928	-0.37	-0.76	0.02	0.062
Covariates adjusted for the above-listed variables																				

TABLE 4. *Continued*

Variables Included in the Model	Overall SNAC Score			Practical and Physical Needs			Lifestyle Changes			Psychosocial Issues			Information Needs		
	β	95% CI	P Value	β	95% CI	P Value	β	95% CI	P Value	β	95% CI	P Value	β	95% CI	P Value
Current unemployment	0.17	0.01 0.33	0.039	0.33	0.17 0.51	<0.001				n/s			n/s		
Ascites (no)	0.24	0.03 0.45	0.022	0.42	0.18 0.65	0.001				0.37	0.08 0.66	0.012	n/s		
Hepatic encephalopathy (no)	n/s			n/s			n/s			n/s			0.49	0.15 0.84	0.005
Portal hypertension (no)	n/s			0.33	0.15 0.5	<0.001	n/s			n/s			n/s		
Dyslipidemia (no)	0.19	0.02 0.35	0.024	n/s			0.3	0.02 0.57	0.036	n/s			0.28	0.06 0.5	0.013
Anxiety/depression (no)	n/s			n/s			n/s			0.34	0.13 0.55	0.002	n/s		

Note: Reference category in brackets unless specified. Multivariable linear regression model included Child-Pugh class, age group, recruitment hospital, marital/live alone, place of residence, diabetes, and primary liver disease etiology.
*Overall significance *P* value < 0.05.
Abbreviations: n/s, not statistically significant; ref, reference category.

live alone" (vs. "have a partner/do not live alone"; *P* < 0.007), NAFLD/NASH as the primary liver disease etiology (vs. alcohol; *P* = 0.010), presence of portal hypertension (vs. absence *P* < 0.001), ascites (vs. absence; *P* = 0.001), and current unemployment (vs. employment; *P* < 0.001).

Three factors had positive β values denoting higher needs for "lifestyle changes," Child-Pugh class B (*P* = 0.001) and C (*P* = 0.028) compared with Child-Pugh A, NAFLD/NASH as liver disease etiology (vs. alcohol, *P* = 0.009), and dyslipidemia (vs. not; *P* = 0.036). When the analyses were repeated adjusting for other metabolic risk factors in addition to diabetes (body mass index, dyslipidemia, and hypertension), the adjusted β values for NAFLD/NASH compared with alcohol as liver disease etiology were similar to those presented in Table 4 (data not shown).

In addition to Child-Pugh class (*P* < 0.001), higher scores for "psychosocial issues" were significantly correlated with "no partner, do not live alone" (*P* = 0.001), having ascites (*P* = 0.012), and anxiety/depression (*P* = 0.002). Having dyslipidemia (*P* = 0.013) and encephalopathy (*P* = 0.005) were significantly correlated with higher scores for "information needs."

Negative β values denoting a decrease in SNAC score were seen for age group and place of residence (outside a major city vs. major city area). Older patients had lower levels of unmet needs in all subscales and overall. Compared with patients of working age (18-64 years), for those aged ≥65 years, the overall SNAC score was reduced by 0.28 (β = −0.28, 95% CI −0.43 to −0.14, *P* < 0.001). Patients living outside a major city area (vs. their major city counterparts) had significantly lower "information needs" scores (*P* = 0.006). In bivariable analysis, place of residence was negatively correlated with the "information needs" score (β = −0.36, 95% CI −0.60 to −0.12, *P* = 0.004), and not correlated with the overall SNAC score or the scores for other subscales (*P* > 0.05). Compared with patients living in major cities, among those living outside major city areas, fewer patients had a first language other than English or were born outside Australia, and a higher proportion lived in most disadvantaged areas. When socioeconomic status, country of birth, and first language were also included in the final multivariable model, place of residence remained negatively correlated with "information needs" score (β = −0.41, 95% CI −0.68 to −0.15, *P* = 0.002).

Discussion

In this large cohort of patients with cirrhosis (33.2% decompensated) from multiple centers, most participants (81.2%) reported that they needed "some" or "a lot" of additional help with at least one item on the supportive needs assessment tool. Not surprisingly, patients with more advanced cirrhosis (Child-Pugh class B and C) had a higher level of moderate-to-high unmet need items than patients with compensated cirrhosis (Child-Pugh A). However, the *level* of unmet need and the specific items requiring additional assistance differed according to patient age and liver disease severity and etiology. The SNAC tool may be used at or before patient consultation to identify needs, monitor resolution of unmet needs identified in previous visits, and detect emerging needs. For example, a patient with NAFLD/NASH cirrhosis who reported having moderate-to-high unmet needs due to difficulty with tasks around the home may benefit from further communication and discussion to enable appropriate referral to targeted support services.

Our data concur with previous studies that demonstrated impairment of HRQL and other patient-reported outcomes in patients with advanced liver disease, regardless of the cause of cirrhosis.[12,21-23] A number of generic and liver-disease specific tools have been used to assess the impact of liver disease on patients' well-being, fatigue, work productivity, and activities of daily living.[23,24] Coping with these challenges can be overwhelming for patients, and many, but not all, will require assistance to manage these concerns.[22] The SNAC tool is unique because it can be used in the clinical setting to identify issues that patients are living with, and highlight the level of assistance, if any, that is required. Moreover, the SNAC questionnaire addresses the demand for better tools that can help to identify which patients would benefit from earlier supportive and palliative care referral.[15] Further work is needed to assess the feasibility and implementation of use of the SNAC tool in the clinical setting.

A key finding in our patient cohort was the increased need for help with "practical and physical" issues with progressive severity of cirrhosis. In particular, patients indicated a moderate-to-high need for help with common, debilitating symptoms of cirrhosis such as lack of energy, tiredness, poor sleep, feeling unwell, and difficulty with tasks around the house. Although

HRQOL may improve with specific treatment for cirrhosis and its complications,[25-27] additional support is clearly required, particularly for patients who may not be eligible for liver transplantation. The cause of fatigue in chronic liver disease is complex and multifactorial, likely involving neuromuscular dysfunction and altered central neurotransmission associated with reduced motivation, cognitive difficulties, and altered mood.[11] Management of fatigue remains challenging in the absence of evidence-based specific therapies. However supportive management focusing on controlling contributing factors and educating patients to better manage fatigue are useful clinical strategies.[11]

Patients with Child-Pugh C cirrhosis had fewer "information needs" compared with Child-Pugh A and B. Possible explanations for this include a longer duration of disease in patients with Child-Pugh C cirrhosis, providing more opportunities to receive information, along with a greater "lived experience." Patients with advanced cirrhosis may have accepted the palliative nature of their disease and therefore require no further information, or they may have been referred for palliative care support and therefore do not need additional help with information about cirrhosis. In addition, patients with Child-Pugh C cirrhosis may be affected by hepatic encephalopathy, which obscures their appreciation of what information they lack. Although patients with cognitive impairment that could interfere with participation were excluded, covert hepatic encephalopathy may affect the reliability of patients' perceived needs. The reason for the lower "information needs" scores for patients living outside major city areas remains unclear.

Our study found that compared with compensated disease, patients with decompensated cirrhosis had greater need for help with psychosocial issues and lifestyle change. Six of the 10 most prevalent moderate-to-high unmet needs related to psychosocial issues, including "worry about … illness getting worse," "anxiety … stress," "feel(ing) down or depressed," and "lack of interest." These findings are consistent with previous research reporting that nearly 1 in 6 patients with cirrhosis in the United States have moderate-to-severe depression, and nearly half have significant anxiety.[14] Depression and anxiety are key contributors to a decreased HRQOL in patients with chronic disease, and may affect many aspects of care including engagement with social risk behaviors (e.g., alcohol, drugs) and adherence to medications and medical

appointments.[12,28] Embedding mental health and social workers in the multidisciplinary care of patients with cirrhosis may help to address these difficult unmet needs, although substantial hurdles related to cost and access to allied health professionals will need to be addressed.

Importantly, our data show that younger age is associated with a greater number of moderate-to-high unmet needs, and this relationship persisted following adjustment for disease severity, liver disease etiology, and other key sociodemographic factors. Although our study did not investigate reasons for this association, younger patients of working age may be more likely to have a dependent family, which would exacerbate the emotional, financial, and practical burden of cirrhosis. Additionally fatigue and sleep issues may be far more impactful to younger employed individuals than a retired person. Younger patients may have fewer comorbidities and therefore be less prepared than older patients with comorbidities to deal with the practicalities of living with cirrhosis and attending hospital appointments for treatment. The SNAC tool asks whether patients had an issue or concern in the past month, and it possible that older patients with a longer duration of cirrhosis may have had their needs addressed. In a recent study of 402 outpatients with cirrhosis (mean age 56.4 [SD = 9.7] years), younger age was independently associated with lower HRQOL, based on the Chronic Liver Disease Questionnaire.[29] However, few studies have examined the impact of age on the patient's perspective of living with cirrhosis or the supportive care needs in this patient group.[15] In contrast, more is known about the impact of age in patients with cancer; studies including patients with melanoma, breast, prostate, and colorectal cancers have also identified younger age as a predictor of increased unmet needs.[30-32] Although patients with melanoma report high needs related to psychological issues,[30] the needs of patients with breast, prostate, and colorectal cancers crossed all domains.[31,32]

Another key finding was that regardless of liver disease severity, patients with NAFLD/NASH had a higher rate of moderate-to-high unmet needs than other liver disease etiologies, specifically in the areas of lifestyle change and practical/physical needs. Compared with alcohol or HCV-related cirrhosis, patients with NAFLD/NASH had a higher prevalence of moderate-to-high unmet needs around "lack of energy," "difficulty with daily tasks," "swelling of ankles/legs," "mak(ing) lifestyle changes," and "experience(ing) side effects of treatment." Our data support a previous study that identified a significant impairment of physical health-related patient-reported outcomes in patients with NASH and advanced fibrosis or cirrhosis, in comparison to patients with chronic HCV.[33] Similarly, a focused literature review found that patients with NASH cirrhosis had lower HRQOL, particularly involving physical health/functioning, emotional and mental health, compared to patients with noncirrhotic NASH.[34] However, it was acknowledged that little information was available about the impact of these problems on patients' daily tasks around the house, job performance, and family life.[34] Although our multivariable analysis with adjustment for metabolic factors showed similar rates of unmet needs as the main analysis, further studies should examine whether varying levels of complexity of diabetes management, as well as of hypertension and other metabolic factors, have an influence on patients' needs.

This study comprehensively identifies the specific unmet needs of patients with cirrhosis using a validated tool. Strengths of our study include the large, multicenter cohort and the assessment of cirrhosis severity, etiology, comorbidities, and complications by clinicians. Patients were recruited from hepatology clinics in large metropolitan hospitals, and those with cognitive impairment (e.g., overt hepatic encephalopathy) or inability to communicate were not interviewed. Therefore, findings may not be directly generalizable to all patients with cirrhosis in Australia, particularly patients from a non-English-speaking background and those living in regional and remote areas. Nevertheless, the study demonstrates that people living with cirrhosis, particularly decompensated cirrhosis, confront numerous challenges, and many patients will require assistance to manage these issues. Use of the SNAC may allow clinicians to adapt their approach to delivering care to the level of patients' needs and preferences.

Delivery of effective supportive care will require an integrated approach with various disciplines and agencies working collaboratively to provide person-centered care. An example of a framework to guide planning this service provision is the Supportive Care Framework for Cancer Care, originally formulated by Margaret Finch in 1994.[35] This framework, designed as a tool for cancer care professionals,

provided a tiered estimation of the supportive care needs of patients with cancer. Patients with advanced liver disease also have significant psychological, social and financial needs, and these needs require identification and support as part of their chronic disease management.[22] However, compared with this cancer framework, the work on needs assessment and provision of support services for patients with cirrhosis is in its infancy. As cirrhosis may be a progressive disease, longitudinal data identifying the extent of and variability in unmet needs with changing disease severity are required. Further investigation of the role of supportive care in modifying preventable cirrhosis complications, hospital admissions, and mortality in patients with decompensated cirrhosis is also needed. From an international perspective, our findings may be relevant to other high-income countries with universal health care systems and provide insight into the potential factors associated with unmet needs and guidance for focus areas for further research.

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